Olmstead Commission
Focus Groups
March, 2002

1. Existing services

Belcourt

Transportation:
- Transportation provided through REM for DD (additional vehicle needed)
- Voc Rehab provides medial transportation long distance
- Retirement homes provide some transportation services
- M-F for 60 and older – rides can be scheduled

Case Mgt:
- Case mgr for DD – travels from Devils Lake (services provided by REM)
- No case mgt, except for Human Serv Dept (minimal)
- Case mgt available for those w mental disabilities

Housing:
- Homemaker assistance for DD – teaches independence w ADL's

Employment:
- Employment for DD through Turtle Mountain Support Services
- Emp services available for those w mental disabilities/not physical

Alternative Services:
- Limited respite care for DD through PATH
- No respite care for elderly
- Turtle Mountain Support Services – day care, independent living assistance for DD 21yo and older
- No alternative services for elderly

Other:
- Alcohol & drug treatment facility – has no licensed addition counselors
- Good IHS services

Bismarck

Transportation:
- No public transit; Taxi 9000, Bis-Man transit MA provider (quality issues – not user-friendly); not meeting demands

Case Mgt:
- case mgt for elderly w physical disabilities

Housing:
- Supportive home care; group homes
- ISLA is very limited

Employment:
- Job coaching; voc rehab
- supportive employment

Alternative Services:
- Day services
- family support services
- supportive respite services
- homemaker services (difficult to find 24h services)
- respite care for elderly

Other:
- school services
- home health if meets criteria

Bottineau

Transportation:
- Bus in town 4d/wk – must make reservation; full to capacity (discourages use); not available evening/weekends; no door-to-door assistance

(Existing Serv – Bottineau, cont'd)

Case Mgt:

- Provided by county SS

Housing:

- Homemaker, personal cares, respite care, chore services, family home care – capacity to meet demands fluctuates

Alternative Services:

- Easter Seals provides respite care for children – costly
- Local providers in community do elder respite care – private pay
- Meals on Wheels – frozen meals pick up at Senior Ctrs in smaller rural communities
- Assistive devices

Other:

- Senior Companion program just starting

Carrington

Transportation:

- Transportation 4d/week in Harvey & Carrington

Case Mgt:

- Outreach services
- Case mgt through school

Housing:

- Group home for DD, Have It (employment serv, transportation, case mgt)
- Housing assistance
- Group home in Carrington & Harvey
- Independent living apt (with staff) for DD
- Assisted living
- Fourth Corp is provider in New Rockford

Alternative Services:

- Respite services (Have It & Easter Seals)
- Homemakers/HH services (2 staff)
- Senior Companion program
- Senior ctrs in Harvey and Carrington

Other:

- PT/OT through school system
- Public health
- Meals for elderly
- Green Thumb
- Infant dev program
- Headstart (income qualifications)

Devils Lake

Transportation:

- transportation through Senior Meals & Services
  - after hours cab rides
  - MA providers for medical apt

Housing:

- 5 group homes (Lake Region Corp & REM)
- ISLA (REM, Fourth Corp)
- SLA (Lake Region Corp)
- 2 adult foster homes
- congregate low income housing
- Lake Region special ed (school system)
  - Group home
  - For kids w behavioral issues
  - Combined funding sources

(Existing Serv – Devil's Lake, cont'd)

Employment:

- day activities, sheltered w/s (Lake Reg, REM)
- Supportive employment (Lake Reg Corp)
- Extended services for DD/MI
- Transitional services between school to 21yo
  - AETS
  - Cooperative program focuses on job training
- voc rehab supportive employment

Alternative Services:

- Respite services (Easter Seals, REM)

Information/Data:

- resources for the deaf (Deaf School)

Other:

- consultative vision program for elderly
- homemaker services
- psychosocial rehab center
- crisis response unit
- dialysis services

Dickinson

Case Mgt:

- through county

Housing:

- 6 group homes for DD (ISLA)
- structured residential program for MI
- Independent living provider
- Assisted living
- Transitional services for DD through school

Alternative Services:

- Meals on wheels, transportation
- Nursing home provides adult day care; overnight respite
- Able provides adult day care for DD
- Senior Companion program handling demands

Other:

- Community action social center for mental disabilities (meals, social activities, payee services)

Fargo

Transportation:

- Public Transit – not enough hours/days
- Senior Commission -- up to 4pm only, 5d/wk, notify 24h ahead, not always available
- Handiwheels – costly ($3/ea way, accepts MA)
- Paratransit (MAT) -- $2, ADA eligible, 15min window in pick-up, scheduling problems
- Medivan – medical/NH visits, does long-distance and in-town; costly
- Readiwheels (FM Amb) -- $15/one way; helps in and out of home
- Senior Bus
- Care-a-van
- Doyle Cab – discount door-to-door w assistance for disabled and elderly
- Private DD residential program providers – some have own transport

(Existing Serv – Fargo, cont'd)

Case Mgt:

- SE Human Serv – DD, MI, CD, Social Worker in schools (referrals through school/parent/health care prof)
- County – elderly & disabled (MA & others)
- Outreach – across 6 cty region; connect elderly w services; made known through newsletters/institutions
- Hospital case mgt
- Professional – referrals through schools, families, community-at-large
- Lack of uniformity in expectations, lack of shared knowledge, strong pro-nursing home bias, staff overload/lack of ability to truly self-manage cases
- Need to allow for self-case managing – more choices/less restrictions

Housing:

- SLA (supportive living arrangement) & ISLA (independent supportive living arrangement) for DD – adults live in own apartment
- Adult foster care
- Private providers (Comfort Keepers, Tami's Angels, HomeWatch Care Serv) – costly
- New Horizon's Manor – assisted living
- Funding – MA eligible (waiver); SPED (personal assistance, respite, adult day care)
- SRO – single residence occupancy
- Red tape with QSP – needs to be streamlined
- DD group homes (no upper limit to stay – up to 5y)\
- Dakota Pioneer/Dakota Alpha
- New Life Center (few beds)
- YWCA
- Ranch – transitional & long-term
- Youthworks – young adults
- Limited hours available in supported living, very restrictive eligibility standards, no 24-7 services available, based on financial limitations not the needs of the person, different standards for different types of disabilities

Employment:

- Supportive employment services; Extended Voc Rehab – DD providers
- Senior Commission Employment Services (AARP) – low income seniors job training
- Experience Works (Green Thumb) – training & employment serv over 65 (? Income test)
- Job Service – rural outreach program for elderly
- State Voc Rehab
- Sheltered workshop environment (SEHS & other DD providers)
- Job coaching (Voc Rehab) – large demand from MI/CD; 6 wk waiting list
- Transportation difficult to evening jobs
- Lack of appropriate supervision

Alternative Services:

- Adult day care, Senior Companion program, service org
- HCBS (Home & Community Based Services) for aged & disabled
- DD waiver as part of supportive home care
- Family support for child w mental health diagnosis
- Easter Seals
- Supportive home care for children – a waivered service
- Community living services (Fraser) – qualified service provider, SLA/ISLA providers
- Home health agencies
- Senior Companion Program
- Meals on Wheels
- Older blind grant – help maintain 55yo and older w visual impairment at home
- Children w mental health – CLS
- Intensive at-home services
- Crisis beds
- Family Care Options – DD child cared for between 2 families (small program)

(Existing Serv – Fargo, cont'd)

Alternative Services:

- Centers for independent living
- Social Club
- Senior Centers
- Restrictions in compensating friends/neighbors
- No transitional services for elderly
- Eligibility problems – QSP/respite care through friends/neighbors (considered subcontracting)

Information/Data:

- Educational Resources (AARP)
- Decentralized information & referral phone lines – Senior info line (needs to be marketed), toll-free MH line, HS ctrs have line for infants, website (crisnd.com), FirstLink, DHS Aging Services Div
- People find out about services through Hotline (237-SEEK), housing authorities, Ctrs for Ind Linging, work of mouth, family members, Senior Commission

Other:

- Guardianship
- Adult protective services
- Client assistant program (Voc Rehab)

Fort Totten

Transportation:

- vans for elderly transportation

Housing:

- independent living apt units

Alternative Services:

- assistive technology assesses homes and find resources
- meals on wheels
- HCBS

Other:

- spec ed services
  - kids attend school in Devils Lake
- tribal Public Health nurses
- county home health services
- lack of access to local medical care
- State-wide training for QSP (if referred by cty SS – at no cost)

Ft Yates

Transportation:

- Bus available w limited hrs (Setting Bull College) only goes early AM and late afternoon/evening
- IHS referrals to medical apts outside the reservation (costly)

Case Mgt:

- CHR program (IHS funding) provides referrals and info on services
- Wrap-around services for children (only 1 staffperson for all of Standing Rock)

Housing:

- Elder housing units – no services

Alternative Services:

- Public school has day treatment program for kids unable to function in the classroom
- Alpha – ISLA; adult day services

Other:

- Elderly & handicapped protection services
- Sioux County public health provides Home Health aides
- IHS Hospital
- Family care

Garrison

Transportation:

- Transportation (fixed route --- certain days)

(Existing Serv – Garrison, cont'd)

Case Mgt:

- Community resource coordinator (hospital based; helps connect people w services, grant-funded)

Housing:

- Basic care in Wilton, family home care, independent congregate living w minimal services
- Family foster homes

Alternative Services:

- HH care, lifeline, extended care services (private pay), homemaker, personal care services, case mgt, adult foster, adult day services
- Institutional respite care (hospital based) for up to 2 weeks

Other:

- Indigent med program

Grafton

Transportation:

- MA transportation providers
- Walsh county transit (goes to GF 2x./week, Fgo 1x/month)
- Providers provide transport to & from jobs
- Busing for elderly

Case Mgt:

- Case mgt & psych services for DD through NEHS
- Some transitional services for DD through Dev Ctr (coordination between schools and NEHS)
- Case mgt psych services therapy for MI

Housing:

- group homes (DD) 3 in Grafton, 2 in Park River
- supported living arrangements (DD) – apt w minimal staffing services
- Adult family foster care
- Family therapeutic foster care
- Living arrangements for elderly & disabled w congregate meals
- REM & Friendship Inc are DD providers
  - residential
- Indep living apts for elderly (have waiting lists)
- 2 SNF's

Employment:

- DD day services (voc programming, supported employment, job coaching)
- REM & Friendship Inc are DD providers
  - Voc day programming
- Developmental Ctr residential program and training
  - Community based employment

Alternative Services:

- adult day services (REM)
- Respite care available through Dev ctr for under 30d
- Easter Seals
- HCBS services through the county
- MH services provides by NEHS on campus of the Dev Ctr
- Green thumb (chore services)
- Senior centers
- REM & Friendship, Inc
  - In-home family support w respite services

Information/Data:

- Foster children 16yo – independent living course

Other:

- Outreach program – work w private providers w clients who have behavioral issues to prevent placement at the Dev Center
- Medication administration for mental disabilities

(Existing Serv cont'd)

Grand Forks

Case Mgt:

- Care Coordinator for children

Housing:

- New Horizons
- DD residential programs (group homes and apartments)
- Basic care and assisted living
- Adult family foster

Employment:

- Employment opportunities (can be improved)
  - Job coaching
  - Sheltered w/s
  - Day support
- Agassiz Enterprises provide a work environment for DD

Alternative Services:

- Easter Seals – respite and in-home support
- in-home staff (short on staff available)
- QSP's 18month waiting list for DD
- Senior Companion program (need more companions) income qualifications make it difficult to recruit
- Adult day care
- Listen Day program DD adult day services

Information/Data:

- School for Deaf provides resources and info re: deafness, ASL
- CSD providers interpreters

Other:

- meals on wheels
- Community Action agencies
- Public health – home visits for frail elderly and wothers w disabilities
- Drop – in – Center for social activities

Jamestown

Transportation:

- Transit 7d/week (schedule a ride)

Case Management:

- Outreach services – senior centers – assessments & link up w services
- Freedom Resource Ctr – outreach from "womb to tomb" for disabled

Housing:

- Meals on Wheels
- Alpha – chore services
- ISLA
- HCBS – adults w disabilities, inc elderly – personal care and respite
- HH agencies
- Post House – subsidized housing (disabled & elderly)
- Transitional (1y) living in house for DD to learn to live independently

Employment:

- Prog enterprises – job coaching, social activities

Alternative Services:

- In Home and respite for children w disabilities (Easter Seals)
- Senior Companion program – not enough supply
- Senior Centers – social activities; respite program
- Senior Ctr – loan services for adaptive equipment
- Senior Centers – respite program
- Easter Seals overnight respite

(Existing Serv cont'd)

Langdon

Transportation:
- transportation
  - during week
  - scheduled days/month to Grand Forks and Devils Lake

Case Mgt:
- case mgt through reg HS center (DD, VR, MI)
- Outreach workers (Aging Serv)

Housing:
- Independent living apt complex
- Congregate housing connected to SNF

Employment:
- Vocational and residential program (sup emp & job coaching)

Alternative Services:
- day care services for adults
  - Lake Region Corp
- Respite for children & elderly (Easter Seals)

Other:
- HH aides & homemaker services (4 staff)
- Assistive technologies IPAT (sunsets this year)
  - Loan library
- vision consultation for elderly & eyeglass program
- Psychiatrists come out to nursing homes
- Ombudsman through HS ctr
- Adult protective services

Minot

Transportation:
- Bus weekdays 7-6pm (in town only), some service on weekends
- County bus 1-2d/wk, depending on county

Case Mgt:
- Community resource coordinators – hospital working w underinsured; connecting people to services

Housing:
- ISLA (3 providers) – short on funding
- HCBS family support – respite for young disabled
- ASI apartments for disabled – 24h aide; capacity stretched; staffing shortages
- Assisted living (3 providers) – capacity full, new ones being built
- Adult family foster care – for elderly; 12 providers in Minot)

Employment:
- Voc rehab

Alternative Services:
- Senior Companion program – functions well, goes out into county
- Meals on wheels
- Senior ctrs outreach workers
- No adult day care
- Homemaker services (respite/chore) – costly for self-pay; people don't know where to go
- Home health

Other:
- Parish nurse program
- IPAT – assistive technologies
- Low vision modifications

(Existing Serv cont'd)

Mott

Transportation:
- senior bus (reservations needed)

Case Mgt:
- case mgt through county

Housing:
- Group homes for DD
- Assisted living

Employment:
- Sheltered w/shop

Alternative Services:
- respite care
- meals

Other:
- HSCB w variety of providers
- HH agencies
- PH strong w home maintenance

NewTown

Transportation:
- Minimal transportation (60 & over) (MHA Elder program – Tribal funded)
- Transportation to medical facilities for elderly & disabled (CHR – tribal funded)

Case Mgt:
- Referral Services (funded by Northland Health Care)

Housing:
- Assistance for elderly in homes/ADL's (MHA Elder)
- Assistive devices (MHA Elder)
- Referral services (MHA Elder)
- Home health available through CHR

Alternative Services:
- Meals on Wheels

Other:
- County nursing services limited (MD referred)

Watford City

Transportation:
- No transportation services in county, w/in city nothing after 4pm (no door-to-door service)
- Very limited case management function (required MD approval)

Housing:
- Housekeeping services/ADL assistance (very limited – lack of providers, no chore providers; costly self-pay)
- Assisted living – congregate meals
- Volunteer Corps provide assistance w house upkeep (yard work, etc.)

Alternative Services:
- None exists for people w disabilities
- Nursing home does some day care (weekdays days only)
- Meals-on-Wheels (w/in city limits)

Wahpeton

Transportation:
- Senior Center has vans (schedule a ride for medical appointments
- Bus scheduled a few days/week
- ISLA providers have some transportation services
- Taxi service

Case Mgt:
- HCBs case mgt through county for elderly

(Existing Serv – Wahpeton, cont'd)

Housing:

- ISLA/SLA
  - Red River Human Services provides support to people living in homes
  - 6 group homes (DD)
  - HCBS – transitional
  - 2 congregate care (elderly)
    - adult day care
  - 3 ICF MR homes
- adult foster care
- Newly built assisted living (costly)
- Apt complexes for elderly (not real accessible, no services)

Alternative Services:

- respite care (day)
- volunteer caregiver transportation/chore/errands/companionship
  - grant funded
  - receives donations
  - provides for MA and those who cannot pay
- HCBS – homemaker, family home care (4 homemakers on staff)
- IPAT (assistive technologies – state-wide)
  - Provides for all incomes/ages
  - direct services
  - federal funding
  - loan library for devices

Other:

- HH
- meals on wheels
- Psychosocial rehab center for social activities
- Senior Meals & Services (senior meals, foot care, Title III services)

Williston

Transportation:

- Transportation
  - Taxi (costly
  - Senior bus 8-3pm weekdays

Housing:

- 10 bed transitional living for MI
- SRO for MI and homeless (3 beds) just starting up
- Group homes & ISLA (Opportunity is provider)
- Adult foster
  - Takes most private pay
  - MA reimbursement too low
- Housing
  - Low income apts
  - 2 basic care facilities for elderly
  - congregate housing w minimal services (costly)

Employment:

- voc rehab supportive employment (on job sites)
- sheltered w/s (TriCity Minot)

(Existing Serv – Williston, cont'd)

Alternative Services:

- Adult day services
- respite through Senior Companion program
  - very limited
  - LSS manages

Other:

- Senior companion program
  - Rural recruitment difficult
  - Transportation provided
- Juvenile assessment ctr

2. Obstacles:

Information/Data:

- Lack of knowledge – don't know what questions to ask
- Find out about programs through medical providers/SS – many people don't know about services
- Lack of information on services available
- No tracking systems
- Rely on other agencies to get word out; directory available; newsletters/radio
- Lack of knowledge, no services available, geographic access
- Information not readily available
- Waiting lists, bureaucracy, lack of knowledge, motivation on the part of the client
- Families usually unaware of services until problem occurs – usually referred through school
- referring staff lacking full knowledge
- finding out "by accident"
- don't know what questions to ask
- assume if don't quality for one program, won't qualify for another
- lack of knowledge re: services
- people "stumble on" information
- find out about services by searching out on own, word-of-mouth;
- Need a "hotline" for service info
- lack of awareness of services
- too much paperwork for clients (need help in filling out and then may not qualify)

Funding Issues:

- Recipient liability for MA (can disqualify for other programs)
- Asset test for MA (been remedied for child/preg women)
- Income guidelines – creates lack of Senior Companions
- Eligibility gaps
- Institutional bias (90/10 funding split)
- SSI – for elderly not qualifying for Social Secrurity (do not incur recipient liability)
- Lack of statewide appropriations for HCBs
- QSP system does not run smoothly; people are required to wait for long periods in order to be paid; no benefits, no safety net for services
- Lack of human resources for HCBS
- Lack of resources
- Relinquish custody to access services
- Funding
- Restrictions on funding (no funding for maintenance level health care; mineral acres asset; disability impairment not severe enough)
- Limited capacity/limited funding
- With grant programs – funding is used up prior to services actually being delivered and benefit reaching consumer
- Lack of funding for prescriptions
- Need to allow for costs for marketing – state doesn't reimburse for mktg
- lack of sufficient $$
- income/asset restrictions
- recipient liabilitiy
- confusion re: MA
- eligibility criteria too restrictive
- way things are funded (way too restrictive)
- state is funding only certain number of slots
- MA recipient liability
    - Disincentive to work
    - "punishing the disabled for working"

(Obstacles - cont'd)

Communication/Staffing Issues:

- Insufficient staff to deliver programs
- Don't like sharing information – private people
- SS system is intimidating (become involved when a problem has surfaced) – carries a stigma – public health perceived more positively
- lack of interagency communications (schools w transitional students
- problems w agency "turfism"
- shuffling of clients between programs
- information is withheld because it would cost the agency $$ (get shuffled to another agency)
- coordination between agencies
- lack of sufficient case manager staff time
- lack of trained, local staff
- overload for case mgrs
- Based on medical model ("silo" mentality)
- not enough QSP's
- Service delivery is so complex
- case management "if you're lucky, you get a good one and get access to services"
- Lack of coordination of services between schools, churches, businesses & the service provider
- Services must be culturally sensitive

Other:

- Geographic distance
- Demographic shift in rural areas (lack of younger people to provide services)
- Misconceptions re: state agencies & reservation gov structure
- No services exist for people w Autism
- geographic distance
- rural
- Smaller school systems don't have comprehensive services (i.e. job training)
- Lack of access to medical care

3. Improvements needed:

Transportation:

- Errand drivers needed
- Lack of sufficient transportation for employment possibilities
- Need a bus to drive people to Dr.'s apt
- Companion to accompany on Dr's visit (written documentation from MD to other providers)
- Need transportation for basic needs (grocery buying, etc), getting to appointments, long distance, after h & weekends
- Transportation to medical appointments (out in county)
- People w CDL's – to drive buses (difficult to find/train people)
- Vehicular conversions to accommodate disabilities
- Need medical transportation (current paperwork for MA transport is too burdensome)
- Need weekend service
- For medical transportation
- Need transportation services
- Need handicapped accessible vehicles
- Need accessible public transit
- transportation stops at 9pm; need for employment and social integration
- costly related to wages earned
- no transportation in rural areas
- no travel out of town
- transportation to medical apts varies from community to community
- vehicles may not be accessible
- Expanded bus services
- low cost transportation for social/recreational activities
- transportation must be scheduled a few days in advance
- Need affordable transportation
- medical transport w escort (long distance; state pays for mileage $.25/mile, won't pay for escort) state of MN provides training to providers
- no state-wide transit
- need affordable, flexible, accessible transportation
- travel voucher system
- lack of transportation for rural
- transportation services costly compared to wages, hours of coverage not adequate
- fixed route public transit doesn't cover entire city, hours of service not adequate
- rural transit only 1x/month
- Lack of transportation for social activities
- Need transportation for social/recreational and medical activities
- transportation in rural areas
- transportation for long distance medical apt
- escorts to medical apt
- transportation (job coaches and case mgrs are transporting)
- transportation
    - social/recreation needs
    - medical/dental apts
    - lack of transportation services
    - rural transportation doesn't exist
    - need for employment (people riding bikes/walking in winter)
- Community MH services
    - Transportation issues
    - At risk for isolation
    - After 5pm issues
- Fixed route public transit needed

(Improvements needed - cont'd)

Case Mgt:

- More capacity in Children's Mental Health Services – Psychiatrists through entire continuum; wrap-around services
- Staffload is too high
- Lack of adequate staff (MHA Elders)
- Quality review concerns re: Case Mgt by private provider (timeliness/supervision issues – super in DL)
- Lack of Case mgt services
- Case mgt, case mgt, case mgt!!
- case mgt
  - assessment to include peer support person
  - consumer involvement throughout process
  - should have a right to an Independent Assessment Eval (2nd opinion)
  - have an advocate present during assessment
- Clients should be able to choose case mgr and providers
- bounced around various agencies (difficult to find services)
  - need better communication between agencies (SSI, Medicare, MH providers)
  - need benefits coordinator
    - assist in interpreting benefits
    - clearinghouse for "informal" programs also
- Client should define own needs
- "the powerbase is with case mgt who also controls the purse strings. NOT GOOD"
- Lack of awareness of resources and services at CM level
  - Some CM refer/others don't – needs to be consistent
- All case mgt services should be of high quality as measured by effectiveness, responsiveness, continuity, reliability and acceptability to the user

Housing:

- ND should develop a multi-year plan to address needs for: 1) youth aging out special education, 2) individuals w DD living with aging caregivers and 3) individuals who would Lack of affordable, integrated, accessible housing
- private landlords unwilling to accept vouchers (market rate is too low)
- Need more transitional supportive living facilities for impaired youth
- Need lock-up type residential living center for young people
- Neighborhood treatment facilities – short term for crisis situations (2weeks – 4months)
- Home modifications
- Elderly need social interaction (prevent depression)
- Need more Senior Companion Services
- Need local independent living facility for younger people w disabilities who may not be employable
- Accessible housing – adapting current home/apartment
- Lack of housing for 18-64yo
- Lack of Supportive living services
- Need a transitional living ctr
- Need a group home
- Need assisted living facility – young and older
- Need an American Indian living ctr in ND
- assisted living only 1 option
- sm communities need transitional serv for DD
- LT supportive housing – homeless, substance abuse issues
- Social isolation – need social interaction
- More Section 8 housing vouchers
- Affordable housing (low income subsidized housing full to capacity)
- Accessible housing for people w families
- Transitional housing for children w disabilities growing into young adults
- Need housing (esp on reservations)

(Improvements needed - cont'd)

Housing

- Residential facility for those w disabilities
- Congregate living w services
- supportive housing
- Adult & child foster care
- basic care facilities
- Need a nursing home
- need more independent living ($$ limited)
  - current hold on building new group homes, so people needing group homes going to independent living
- Housing
  - Temporary rent subsidies while waiting for Fed Housing Assistance
  - One-time grants for home modifications
  - Incorporate universal design to new housing starts
  - Higher rent allotments in Ssi and SSDI
  - Funding for accessibility projects
  - Expand rehab guidelines to include some access features
  - Housing Authorities mandated to apply for housing vouchers specifically for persons with disabilities
  - Develop a "shared housing program" for trainsition and ongoing
- More family foster homes
- Need assisted living facilities
- handicapped accessibility to bldgs (living spaces and public spaces)
- need to educate landlords re: incentives
- shortage of foster homes
- Need elderly housing w congregate services (difficult to understand assisted living)
- MN has moved from group homes to 1:1 apt dwelling
- affordable housing for middle income
- lack of funding for home adaptations
- housing needs for people requiring some structure
- lack of accessible housing for people w physical disabilities
- housing
  - accessible, affordable housing for elderly and younger disabled
  - assisted living
  - needs to be user-friendly for physically disabled
  - trained staff available
- no adult foster homes for elderly
- need accessible apt for elderly and young disabled
- affordable independent living w services
- public bldgs and spaces not accessible
- housing
  - need affordable, accessible housing
  - no assisted living
  - transition from rural areas, elderly need additional services til adjusted
  - independent living w supervision (SRO's)
  - low income housing for DD
  - elder DD when they leave group home w Alzheimer's care needs
- group homes w services
- adult foster care & children
- shortage of PATH homes
- DD needs de-institutionalization – transition to independent living; no "DD" money for housing; independent resources required for ability to pay for housing
- Housing Assistance Program (existing) – 1y waiting list
- People w "record" having trouble getting housing
- Housing must be safe/accessible (putting in high rise – not safe)

(Improvements needed - cont'd)

Housing

- Public education is needed re: DD issues (responsibility/support)
- Home upkeep/repairs
- Need affordable housing
- Need residential treatment ctrs, group homes for youth
- Need more pro-rated apartments for families who have members who are physically and/or psychologically limited
- Locating a facility ought to be done at the time of neighborhood development
- More Section 8 vouchers
- Huge need for integrated, affordable, accessible hopusing
- Education to builders, architects, apt owners on benefits of having bldgs being accessible (inc tax incentives for barrier removal
- Need different levels of housing w services based on needs
- Shortage of affordablem accessible, integrated housing
- Lack of housing for people w disabilities – accessibility is an issue
- Upkeep issues w homes owned
- Public education needed to overcome negative attitudes
- Access housing is lacking (getting ramps built, remodeling older homes, costly)
- Lack of available housing for elderly
- Need independent congregated housing w services for elderly
- Family, 3-bedroom housing not available
- Home modifications – ramps costly, difficult to find funding if renting (many people w disabilities do not own)
- Need affordable housing – with limited incomes
- Need accessible housing
- ADA requirements need to be enforced (Voc Rehab is prov some assistance) tribes are exempt, except where federal $$ are being used
- Need transitional housing/services for:
    - chronic MI
    - DD
    - Severe physical disabilities
- Rolette County Housing Authority
    - require deposits which many people w disabilities cannot afford
    - waiting list (open to discrimination – not applied w fairness)
    - separate waiting lists for rental/owning
    - have had mold in units so that's taking priority right now
- Hearing dogs need to be allowed, fences should be responsibility of provider
- Need more ISLA/MSLA funding
- No place in community for DD 18yo and older
- Elder independent living – getting more younger people w disabilities (assisted living currently being built)
- Need assistance with home modifications (ramp building)
    - waiting list 2y (creating delay in getting into housing)
    - costly
- Home modification – ramps, wider doorways, larger showers, etc.
- Desperately need more housing in all areas
- Need accessible housing
- Need homeless shelter
- Assisted living ctr for younger disabled – should not be living at nursing home
- Shortage of housing
- People w disabilities move in with families
- Tribe is re-assessing census – multiple families/residence
- lack of accessible, unsubsidized housing
- need for more social activities for people w disabiltities
- Outreach workers assisting w some home repairs

(Improvements needed - cont'd)

Housing

- Funding for chore services (Old Am Act) is stopping – leaves low & mid income w/o serv
- Lack of options in small communites
- lack of accessible larger rental housing units
- DD group homes have a 2y waiting list
- Need elderly assisted living for low/mid income
- MI group homes
- one option "The Manor" primarily elderly, not very accessible
- home modifications for DD funding only available if <21yo
- social activities
- accessible housing that's ingtegrated
- affordable
- assisted living is costly w restrictive criteria for adm & d/c
- rent based on income (expenses not considered)
- home adaptations (Bismarck no longer sending out devices)
- Some discretional $$ available for foster kids
- need for affordable/accessible elderly and disabled housing
- family housing adaptation support is needed to care for elder family member
- Need consistent use of case mgrs
- must be homebound for HH (need housing w day room and services for people)
- difficult to qualify for home ownership (recipient liability)
- lack of common definition of assisted living makes it confusing for people
- funding for home adaptation is difficult
- utilize all funding streams for home purchase, both public and private (i.e. Fannie Mae, ND Housing Finance Agency, HUD, Section 8 vouchers)
- expand upon USDA programs for funding
- make landlords aware of tax incentives and other resources for home accessibility
- make public aware of rental housing discrimination cases
- No family reunification section 8 program
- Increase funding support for ISLA's, personal assistance and other supported living options.
- Transportation to evening jobs

Employment:

- Job coaching for teens
- Employment agency specifically for people w disabilities
- Remove restrictions w MA/SSI when a person gets employed (have to lose MA when employed)
- Overreliance on sheltered workshops – it's the program that's funded, so it gets used, even though it may not be a good "fit"
- Expansions of job opportunities (manufacturing) – requires working closely with potential employers and education on benefits of hiring people w disabilities
- Lack of variety in employment opportunities (i.e. manufacturing)
- Difficult to find day care for children w disabilities
- employment assistance (difficult to find job)
- Need more creativity/flexibility in employment opportunities (job sharing, work crews)
- supportive employment is underfunded
    - lack of creativity – need to tap into additional opportunities in community
- employment
    - education for employers
    - use net income (not gross) to calculate earnings
    - decrease the recipient liability as an incentive to work
    - design & fund new training & cert opportunities
- employment opportunities
- increase employment opportunities by building relationships with employers
- Employment – no incentive to work; penalized when making income; recipient liability "working to pay recipient liability"

(Improvements needed - cont'd)

Alternative/Transitional/Support Services:

- Need more crisis beds
- Need more Family Care Options capacity
- Need more Senior Companions
- Crisis Reponse – children w MH dx
- Respite care needed for DD
- Lack of respite care for elderly
- Need more respite like Camp Grassick (Elks)
- Social interaction opportunities for teens/young adults
- Transition from adolescence to adult (gap in services)
- Need adult day care – funding assistance (private pay/SPED)
- Adaptive equipment – grant funding expired
- Support groups for caregivers and for people w disabilities (serve as information dissemination point)
- MH/CD transitional services needed for people discharged from Jamestown (residential and support)
- people are currently dropped back into the community
- Lack of outreach for the blind
- Loss/lack of interpreters
- Need transitional services for people w mental illnesses
- Need short term respite care when someone require a live-in
- lack of providers for in-home support (paperwork streamlining)
- no respite care for weekends, etc.
- lack of community-based services for people w MI
- day programming needs to be more individualized (funding issue)
- lack of choices in providers
- people w medical & social needs have biggest gaps
    - 2 funding streams
- PCA's should be affordable and consumer controlled
- no elderly Alzheimer's services
- poor transitional service from school to adult ages
- limited Alzheimers' units available – adm/d/c criteria
- lack of services in smaller communities
- implement a "consumer control" model for managing services
- Develop a consumers "tool for mgt" training reference guide
- Need services for clients w highly specialized needs
    - Behavioral intervention
    - "hard cases"
- Need full continuum of services
- Clients need quality of life when they have limited resources
    - Social interaction
    - Travel opportunities/recreational opportunities
- lack of services in rural
- need to improve the referral system
- need funding for respite care of younger children
    - adoptive families have access to services that biological families do not have
    - smooth connection to services inconsistent (w adoption of special needs child)
- Need group homes w greater service levels (medical needs)
- System needs to be more flexible to work around needs of children
- Insufficient in-school services for children with special health needs
- need a central gathering place for seniors & deaf people to decrease isolation
- No outreach component – people enter system in crises
    - Seeing a lot of MH issues in community's elderly
- lack of nutritional support 7d/week

(Improvements needed - cont'd)

Alternative/Transitional/Support Services:

- Mental health services for youth very limited – need some residential ctrs for kids who may need extended treatment
- No services for disabled on reservation
- Transitional services needed for DD ages 18-21
- Enforce laws re: requiring schools to provide services to DD up to age 21
- General lack of services for elderly
- Mental health services for youth not being met in an adequate manner
- Availability of personal services on an as needed basis
- System to care for disabled when parents are no longer around
- MH needs for elderly not being fully addressed
  - Need pysch nursing outreach
- No adult day care
- gap for DD between school system and community (dropped into community w/o services)
- Access to resources for home adaptations
- lack of access to assistive technology
  - lack of vendors
  - lack of awareness by clients re: what's possible
- integration of elderly disabled into senior services (recreational activities)
- respite for elderly
- no transitional setting for DD
- adult day services for elderly
- 24h in-home care for elderly
- no adult day services
- Senior Companion program
- need more social activities for all age groups
- need Alzheimer's care
- respite services for young and old
- respite (lack of caregivers)
  - training is too long – need to make more specific to needs
- increase funding for assistive devices
- Emergency response to children who are suicidal (currently ending up in jail)
- lack of DD services 18-21
- Very few services rural (younger disabled moving into larger communities; elderly lack services; lack of service providers – inconsistent demand)
- gaps in school services where emphasis is on saving $$
- need full continuum of services for elderly w dementia
- coverage for assistive dogs
- respite
  - need increase in funding
  - lack of providers
- assistive devices for visually impaired
- Services (i.e. IPAT) needs to do more outreach
- Services for profoundly disabled beyond 21 years of age (only option is nursing home – lack of social/recreational activities)
- Community-based services for people with disabilities who also have heavy health care needs
- No services for people w disabilities – end up in nursing home (funding available, no providers)
- People w disabilities move to other communities for access to services
- People shy away from services – if there's any perception of being a "bother" or intimidation
- Psychosocial rehab as a core services (inconsistent funding; flexibility in hours)
- lack of services in rural areas
- Increased use of Senior companion program
- Need consumer choice/control model (flexible – individualized – entire continuum)
- Assistive technologies

(Improvements needed - cont'd)

Information/Data:

- One centralized information and referral line – have regional focus for certain populations
- Public health communications campaign (awareness, understanding, access info)
- Need a coordinative function – get information to individuals re: program availability
- Services need to have outreach function (go out to clients)
- Public awareness of projected needs of elderly (future demographic trends)
- People find out about services in haphazard way; needs to be better communication across agencies (i.e. county SS, Human Serv Ctr, hospital-based SS staff, etc.)
- Need better tracking systems w data on people needing services
- Increased community awareness
- Develop a community living intervention hotline
- One stop shop where referrals can access ALL the information they need to remain in or re-enter the most integrated setting (Olmstead hotline)
- MI placement in nursing homes (how much has this happened?)
- lack of knowledge re: services
- Many people find out about services by word-of-mouth/by chance
- Need data/stats on numbers of people w disabilities/diseases
- Quality review/liability issues w home-based services
- there needs to be better inventorying, networking! Agencies are not geared to this. People are left to fend for themselves to find services and to dig for information.
- Need a centralized PR campaign for all services
- ND needs to develop, coordinate and maintain a continuous quality assurance and improvement and reporting process
- ND should review the roles of DD and provider-based CM to determine what QA functions should be performed by each and the CM ratio (to 1:30-45) should be adjusted to reflect those QA functions
- every resident of an institution should have an independent evaluation to determine their least restrictive environment
- needs to be accountability/oversight to ensure services are being delivered

Funding:

- Expansion of insurance coverage
- Gap in funding for middle income w child w MH diagnosis
- funding must follow client
- maintain funding levels for western side of state and rural areas
- Safety Council needs to continue funding for assistive devices
- Prescription coverage
- Working poor (45-50% clients at HS Ctr don't have insurance/MA)
- LTC coverage
- no funding for adaptive equipment
- Billing system -- billing by individual cuts out insurance coverage (non-provider status)
- Insurance portability
- Expansion of HCBS, SPED/Exp SPED, and all waivers
- 50/50 funding split between inst/HCBS
- More funding for Ctr for Indp Living
- Money should follow person (should be determined on person-by-person bais)
- Need incentives for people to care for family members w disabilities
- Need for residential & educational services for children w behavioral needs – currently referred out of town; transition into another school very difficult
- ISLA – funding is inconsistent
- Services for children w disabilities not covered by HCBS
- funds need to follow person
- SPED restrictions (must meet income guidelines; child must meet nrsg home placement screening)
- Funding needs to follow person

(Improvements needed - cont'd)

Funding:

- Programs that work allow person w disability to take the lead (coordinated multi-disciplinary clinics)
- Funding
- SSID – more difficult to become eligible (determined at state level; open to discretion; criteria not applied uniformly) -- significant because a person becomes MA eligible also
- Gap in 62-65yo moving from SSID to Medicare – no insurance coverage during that transition
- need more funding for in-home care
- Need more guardians
- Funding for adaptive equipment
- Increased funding for services (don't put into bricks/mortar)
- Services to DD "more refined" than MI/CD
- DD population has better access to in-home services
- Need more control over who to hire (funding following person)
- funding needs to follow person
- more flexibility in NH bed utilization as basic care
- lack of group homes, sheltered w/s, lack of funding for families to care for DD children
- qualification restrictions
- need more flexibility within programs
- funding doesn't follow person
- funding
    - $$$$ for family caregivers and training
    - funding should follow person
    - low/no interest revolving loan funds for consumers
    - aggregate financil mgt of waivers (combine all waiver funding resources) so limits can be exceeded to improve access to community options
    - hardship waivers for relatives, guardians to fill the service gap
- Expand waiver programs
- guidelines for programs vary & are confusing
    - need to be flexible in adapting to presenting needs
- Increased funding for HCBS
    - Clients are being shuffled between county/state and between programs due to which pocket the $$ are coming from
- Increase in ISLA's and other supportive living options
- Funding should follow individual
- Gap in funding for HCBS for middle-aged
- Increase funding for ISLA (people waiting for years)
- Grafton placements waiting for ISLA (can't get staff)
- Funding should follow person
- DME funding (costly)
- need consistent funding for adult protective services
- funding for guardianship
- need to continue funding for adaptive equipment (through ND Safety Council/Aging Services)
- income restrictions for in-home family support
- income qualifications too restrictive
- asset qualifications too restrictive
- qualification for programs should be needs-based, not income-based
- Many people "falling through the cracks"
- Rules are so tight; no ability to adjust to situation
- Parents giving up custody to get access to services (not MA eligible, maxed out private pay) federal issue
- System is biased toward institutionalization

(Improvements needed - cont'd)

Funding:

- Qualifications restrictions – people falling through the cracks, need a pool of money for those who don't qualify
- MA buy-in "ticket-to-work"
- money should follow the individual and not the institution
- better pay for private PCA's
- restrictions on qualifications need to be lifted

Coordination/Staffing Issues:

- Easter Seals staff coverage
- Coordination & better use of transportation – urban vs. rural; available but not useable
- Staffing shortages related to low wages/hard work/shift work/high burnout; transportation for employees out in the county
- Lake Region Human Services is not helpful – they don't do anything for our clients
- Increase wages for QSP
- Better communication w reservations – currently no cooperative agreements w any reservations (121 Voc Rehab Projects)
- need more awareness by providers re: disabilities (use CEU's requirements as a vehicle)
    - difficult to find providers who understands living w a disability
- staffing problems (sporadic timing), funding, difficult to recruit
- lack of individualized approach
    - put people into a "box"
    - try to fit people into a program, instead of fitting program to people's needs
- staffing issues (wages, difficult to find quality staff)
- Staffing/workforce shortages (low wages)
- Salary/compensation for line staff in residential facilities –difficult to attract quality staff w low wages; labor force availability
- staffing difficulties -- shifts, low wages, quality issues, training, turnover
- need better (more heavy staffing) supported living arrangements
- Staffing issues
    - Low wages
    - Training
    - Retention
    - Workforce availability
- turnover in agency staff
- need inter-agency cooperation (local and regional staff)
- Professionals lack understanding/sensitivity re: deaf culture
- cultural conflicts w deaf community
- No QSP available for chore services
- Better coordination/communication between agencies
- Staffing for ISLA's very difficult (low wages, training is good in ND)
- Need for escorts
- Lack of access to professional services (i.e. OT/PT
- when having trouble dealing with HS staff, people don't know where to go
- staffing shortages (low wages)
    - no increase in funding for staff time (ISLA contracts) since '90's
- limited MH providers (have to travel to GF)
    - support groups are needed
    - limited options for counseling services
    - difficult to find MH providers
- lack of in-home staff
    - paperwork is monumental
- lack of adequate staff (wages)
- case mgt for elderly
    - more staff for CM for DD
- access to medical professionals

(Improvements needed - cont'd)

Coordination/Staffing Issues:

- child in lock-down facility for 90d waiting for MH evaluation
- County Social Services puts too many functions on one person – case mgt, guardianship, etc.
- Conflict of interest for SS staff who function in multiple functions
- Needs to be better coordination/communication between county staff and Aging Services staff
- Labor source for providers – teens/program through school system
- Intimidating system (needs to have more of a customer orientation)
- State government needs cultural sensitivity training
- PCA's; demand greater than supply; difficulties in recruiting (low wages)
    - Get pd same amount for in-town as rural (don't get pd mileage); no benefits; lack of consistent client base (income)
- Lack of awareness/focus on least restrictive environment by professional staff
- Lack of staff in rural areas
- Coordination between programs to project needs in housing (housing rehab program)
- Need more coordination between agencies

Other:

- "No wrong door" policy – refer agency to agency
- "Case Management for system"
- Medical management oftentimes requires institutionalization (cyclic, more support needed at home)
- Need guardians
- Lack of adequate access to medical services (24h) on reservations
- Guardians to help folds w disabilities pay bills, take care of personal affairs
- Need hospice care
- Need a nursing home
- Short term home health care (currently short on staff)
- Standing Rock licensure as a home health provider
- Designated home health care staff for each county/community
- Lack of facility for IP care for children
- crises beds for youth in juvenile justice
- medical psychiatry care
- Guardianship gap for people with MI and elderly (waiting list of 38 people right now)
- need advocates
- Cultural issues
- lack of guardians
- dental care
- prescription costs
- prescription costs

4. Waiting List

- DD group homes have a 2y waiting list
- Anne Carlson waiting list
- Wait for access is too long in crisis or near-crisis situation
- Williston gets 34 Section VIII vouchers (100 people on waiting list)
- Housing Assistance Program (existing) – 1y waiting list
- Voc rehab eval 60-90d (too long)
- Safety, health, cleanliness, basic needs
- Wanting to get out of institution & professional says discharge ok
- Wanting to live in less restrictive environment & prof does not oppose
- Compliance
- Access to provider is not timely (mult-weeks or months)
- There is "cultural shock" when referred to different provider – needs to be taken into account with certain conditions
- Client's choosing another provider not available should not place him/her on a waiting list
- Triaging currently happening in MH system (staffing shortage issues)
- Seriousness of current condition – esp in MH area or in time of physical crisis
- Fit between needs & program services
- Level of stress in family situation
- Alternate options realistically available to family
- Individual preference should be considered (geographic issues; closeness to family)
- Use a point system (preference, needs, income, children)
- Safety should be considered (needs presenting, whether qual serv providers available)
- Capacity of provider should be considered
- Severity of condition
- Potential to live independently (readiness)
- Availability of housing & site chosen
- Availability of referral sources (MD)
- Lack of provider in community
- Timeliness of provider availability (1-2m)
- Some services have strict regulatory requirements for delivering service – i.e. home health visits must occur within 24-48h for Medicare, Meals on Wheels must meet demand
- When service is needed, but not available
- Housing availability – income limitations
- Geographic access
- Type of service needed – prioritization of needs (triaging)
- Must be timeliness standards for evaluation/assessment phase – state is lax right now in getting first step done
- Two waiting periods – evaluation/assessment and access to provider
- Should in-state residents have priority over out-of-state?
- Disabilities
- Low income
- Degree of disbility
- Supportive family members
- Ability to pay on own???
- Level of need
- No services available
- Current waiting list to get child w emotional disorder in residential care (in ND) – 6 months
- Parents are turning child over to Protective Services to be able to access services faster
- Emergency services for mental health – delayed over weekends, red tape with HIS approval
- Services no available w/in reservation
- Home improvement projects – long wait (home adaptations)
- Housing Authority – must update application monthly
- Prioritize critical need

(Waiting list - cont'd)

- bottlenecking occurs when full continuum doesn't exist
- used to document need
- families try to project future needs (1y waiting for basic care bed)
- if services aren't available, people make do (so no waiting list ever gets started)
- people just above qualification guidelines never show up on waiting list
- people are "pushed into" the available services, instead of waiting for more appropriate serv (missing links in continuum; inappropriate placements)
- medically fragile end up in nursing home
- waiting list not appropriate for crises services (lacking)
- being able to project needs
- funding should be projecting for future needs
- geographic access
- 90d for any services
- should be maintained on original waiting list if less optional services are accepted (timeliness/funding issues)
- lack of available services
- Money should follow person
- different for different services
- realistic availability of providers
- prioritized by need
- incentive to have a waiting list is to show need/anticipated future need
- 3y waiting list for housing
- people who qualify for services are getting due to lack of funding and lack of staff
- services not available
- should be no longer than 90d
- keeper/central collecting point for waiting lists
- incentive is to <u>not</u> have one
- Need to acknowledge people waiting for services
- Who is the professional who determines appropriateness for discharge?
- Geographic considerations need to be included
- Private providers can "hand-pick" clients
    - A request top accept is extended
    - No recourse to being discharged by provider (no appeals process)
    - Staff/client issues may trigger discharge
- services/support required by persons w disabilities
- shouldn't be any longer than 90d
- based on individual needs (emergency services)
- first come, greatest need
- placement should be appropriate based on need
- must have some flexibility to get services to people quickly when needed
- projecting future needs in a timely fashion
- should not be a waiting list for health care services
- SEHs regional referral committee meets quarterly
    - Takes all referrals
    - Keeper of the list
    - DD case mgt determines qualification
- person who is getting services (but not most appropriate) is not put on waiting list for more appropriate service (should be)
- 6 months reasonable
- should be no waiting list for guardianships
- goal for intake/evaluation is 7d & 45d for eligibility
- housing is a 6 week wait to process
- assistive technology can be up to a 9mon wait
- 6 week wait for psych evals
- target most needy with lack of ability to pay

(Waiting list - cont'd)

  - rural communities are getting less funding, due to decreasing population, but exp increasing need

- there should be no waiting list
- lack of timely access to MH evaluation
  - had to home school
  - 3 month wait
  - through the school system
- placed on list if services is needed
- maximum of 90d
- will increase as elderly population increased in size and demand for services increases
- need full complement of levels of housing to avoid "bottlenecking"
- geographic distance should be considered
- emergency needs should not be wait listed
- the length of wait depends on the service
- no longer than 30d for in-home services
- when make a referral, there should be a standard for follow up (i.e. the referral should make a contact within ____ days)
- low pay creates the waiting list
- should be standards for review and re-evaluation of waiting lists
- The psychiatrist with the nurses, Psychologist & case managers should make the decision whether a person should be placed on a waiting list
- Housing Assistance Program (existing) – 1y waiting list
- Waiting list for SS referral 3months

5. Institution

- Varies w population – DD: more than 4 unrelated people
- Where services are accessible that are not usual in the home environment
- Where someone else is making ADL (activities of daily living) decisions for you
- Certain privileges/rights have been removed
- For-profit hospitals, lock-up facilities, full-service state-operated facilities
- More than 3 non-related persons for the purpose of receiving services such as housing, assistance with ADL, education and/or medical services
- Nursing homes, Group Homes, ICF-MR, Anne Carlson, State Dev Ctr, State Hosp, Rehab Units, State School for the Blind, State School for the Deaf
- Multiple unrelated people living together
- Confinement
- Not able to leave on own accord
- Services
- 24h residential care
- Choices are restricted
- No working or social life not provided by institution
- Physical/psychological similarities of residents
- Choices are restricted
- Regulatory reviews (federal/state)
- Funding sources
- Unable to come & go as you please
- Impersonal environment
- Staff are degreed professional; higher technical expertise
- Loss of rights/freedoms
- Staff is employed by institution; with community-based services, client hires provider
- No/less choice re: accessing services
- Lack of feeling of a productive member of the community
- Nursing home, hospital, swing bed
- Setting outside the home that provides services
- Residential facility away from home, family & support systems; have paid people to provide services
- Jamestown state facility, nursing homes, Grafton facility, inpatient psychiatric unit – long term care
- Isolated from community – less community involvement, less input from the community
- Far away & inaccessible to family
- No choice re: leaving/staying
- Restrictive (no choice re: going/coming, when to eat, etc.)
- rigidity (have to fit into services)
- not able to direct own care
- system-controlled, not self-directed
- 3 or more unrelated people
- lack of choices (daily living)
- separation from mainstream (may be home if no transportation to various places not available)
- lack of age-appropriate social interaction
- jail
- rights taken away
- locked in
- seclusion
- can't use phone, etc.
- little control over who provides services and how
- 4 or more unrelated people
- restrictions (take away clothing/personal belongings)

(Institution - cont'd)

- comprehensive services
- dictates daily schedule
- quality of life issues are limited (choice restrictions)
- loss of identity
- staff have shift work with multiple caregivers
- lack of personal choice
- physical environment is "institutional" in looks (few plants, animals, sterile looking)
- limited choice in coming/going
- increased paperwork
- no choice in roommates
- segregation (lack of variety in residents)
- 4 or more unrelated persons
- limits on personal choice/options
- restrictive environments
- congregate living greater than 4-6 people
- clients incapable of self-care
- place has caregivers (shared between clients)
- lack of flexibility
- confinement
- safety net
- expectation that client conforms to facility needs
- structured
- lack of integration into community
- self-contained in meeting client's needs
- restricts mobility/choice
- limits full access to community
- individual need defined by others and tr4eatment imposed by others
- highly regulated environment
    - rigid environment due to regulations and lack of adequate funding
- has a feeling like "being in prison"
- structure is a hallmark, need for efficiency
- not build on social model (no funding stream for social model)
- living w people you don't want to live with
- lack of choice in living environment (no individual preference)
- lack of community involvement
- over 4-6 people
- consecutive overnights w required inspections/accreditations (regulatory oversight)
- segregated from community
- unable to take usual risks in life
- no choices
- restrictive
- long-term
- self-contained physical plant
- route/not individualized
- lack of decision making
- 6-8 unrelated people
- > 4 unrelated people
- choices restricted
- it's a "state of mind"
- a building
- rules, guidelines, structure
- someone else decides what you're going to do all day
- loss of privacy
- having to share (loss of personal effects/space)
- nursing homes

(Institution - cont'd)

- facility w 24h care, where everything is provided
- restrictive
- client is unable to care for self
- controlled movement
- mandatory placement
- amount of supervision
- no input into decisions made
- loss of personal freedoms (structure/rules)
- not able to select roommate
- "dormitory feel"
- jail
- lots of regulatory oversight and requirements
- "HOME" – a place where a person's needs and pleasures come first
- Assisted living facilities can evolve into an institution if the services provided are so structured that it removes consumer choice and direction

Other issues:

- Chronic vent patients, total brain injured – no place to go
- Chronically mentally ill are ending up in homeless shelters & prisons
- Need to address services for TBI, ADHD, FAS
- Access to dental care
- Stigma w taking services
- Sufficient income to sustain home
- County/Region boundaries creating many barriers/obstacles to accessing services
- Basic safety/security needs – must be addressed before anything else
- Lack of economic opportunity
- Direct funding to reservations from CMS – assist in bldg nursing home
- Family support needed, esp w 2 income families
- schools are incented (cheaper for them) if child is institutionalized
- "the system makes people feel lucky they are getting what they get, when in fact, they may need more"
- Olmstead issue should be addressed by cities and counties in their comprehensive plans, also
- Establish a State Olmstead Annual Review Cte to ensure compliance, research creative financial options, and evaluate programs